

Financial Healthcare Resources

A growing list of existing organizations that provide financial resources may be located [here](#). Information changes often, however, FARF does it's best to maintain current and up-to-date information on this list.

The Fanconi anemia diagnosis affects every aspect of life, including healthcare, family life, school, social life, and how you make financial decisions. What are the choices when trying to make sure healthcare is covered?

For individuals with FA and their families in the United States, here are some options to consider:

Private Insurance

Private health insurance offered through an employer is extremely valuable to families of children with special medical needs. It's important that you understand what your health plan covers as well as any out-of-pocket expenses for which your family will be responsible.

If you already qualify for health insurance coverage under the terms of an employer-sponsored plan, you **can** apply for income-based Medicaid and receive monthly premium support. Families who are over-income for income-based Medicaid may still be able to access Medicaid through a waiver. Families may also be able to supplement their private health insurance plan through Title V funding or with Supplemental Security Income (SSI) payments (see below).

This means it could be possible for a family of a child with Fanconi anemia to have private insurance as their primary insurance and Medicaid through a waiver or the Tax Equity and Fiscal Responsibility Act (TEFRA) as secondary (essentially picking up any copays or co-insurance for the child). In addition, Title V could provide tertiary insurance, picking up any expenses related to a qualifying diagnosis not covered by the primary or secondary insurance while also receiving SSI payments.

Medicaid

For low-income families, it is important to apply for income-based Medicaid if the child is not covered by a private plan. Medicaid is funded by the state and federal governments and provides necessary medical care for low-income individuals. These programs are available to families and their children up until the day the child turns 19 years old. Federal policy requires that each state have a Medicaid program, but since programs are administered at the state

level, program names and income qualifying categories will vary from state-to-state. To find out about Medicaid programs in your state, visit www.medicaid.gov.

When a child with a special medical need does not qualify for Medicaid based on his/her family's income, it can still be accessed in two ways; through a Medicaid waiver or through the deeming process (which determines financial eligibility) after an extended hospital stay (see below).

Social Security

The Social Security Administration (SSA) administers two different programs: Social Security Disability Income (SSDI), and Supplemental Security Income (SSI). SSDI is provided to adults who qualify as disabled and have worked and paid into the social security system long enough to qualify for the program. SSI is offered to low-income people with disabilities who either have not accumulated enough work credits over their lifetime to access SSDI or who have never worked. SSI benefits can be paid to people at any age, whereas SSDI payments are only paid out to adults.

For children under the age of 18, the SSA provides SSI payments to children in families with limited resources who also meet the agency's definition of disability. Families must first qualify financially for benefits through SSA before the child's disability will be considered.

For those age 18 and older, only the income and resources of the person who is disabled counts. That means that even if a child didn't qualify for SSI as a child with a disability due to the family's income, an adult child may qualify. A child can apply for SSI up to 90 days before his/her 18th birthday. SSI benefits for a new adult can begin as early as one month after their 18th birthday. If a minor child is already receiving SSI benefits, the child will be reevaluated for SSI within a year of his/her 18th birthday.

The definition of "disability" for an adult is different than that of a child. For a child to be considered disabled they must present with significant functional limitations whereas, for an adult, the focus is on the ability to work. This means, if a child did not meet the agency's definition of "disabled" under the age of 18, s/he may meet the criteria as an adult. To be eligible for SSI as an adult, the individual's disability must make him/her unable to work at "a substantial level", which at the current time is to make \$1010 a month or more. In addition, the disability must be expected to last at least a year or to result in death.

Adults receiving SSI benefits are also able to work or attend school. SSI recipients can continue to work and receive benefits until the time his/her pay and other income exceeds the income limits for SSI. The SSA also offers work incentives to adults living with disabilities who wish to work.

Since Medicaid comes along with SSI, if a person exceeds the SSI income limits, Medicaid will be stopped. Even if your SSI payments stop, your Medicaid can stay in place if you are eligible

under a waiver plan. Therefore, it is important to consider applying for a Medicaid waiver even if you are already receiving Medicaid through SSI, as this provides more stability in healthcare financing. When a child has been denied SSI benefits based on their family's income but would have otherwise qualified based on their disability, the child can access SSI payments through the deeming process during the time spent in a hospital after an extended hospital stay. Similarly, if a child has been hospitalized for an extended period and did qualify for SSI prior to the hospitalization, the family will see a decrease in SSI benefits during the hospitalization. This is because, through the deeming process, the government has stopped counting the family's income against the child but also considers the child's living expenses to be close to zero since the child is currently being cared for in a hospital.

To apply for SSI call [1-800-772-1213](tel:1-800-772-1213) to make an in-person appointment at your local SSA office.

Title V Programs

Each state receives a federal block grant to administer a Title V program, often called "Children Special Healthcare Services" or "Children Special Healthcare Needs". The program works a lot like Medicaid but has more lenient financial criteria for qualifying. The associated diagnoses related to Fanconi anemia are considered qualifying diagnoses (hematological disorders, hearing loss, visual impairment, seizure disorders, etc.). This insurance is offered in addition to Medicaid and private insurance, so it should pick up expenses related to the qualifying diagnosis that might get denied by Medicaid and/or private insurance. Children can be covered until their 22nd birthdays.

To find contact information for the Title V programs in your state, [click here](#).

Institutional Deeming

Under the Tax Equity and Fiscal Responsibility Act (TEFRA) children receiving care in an institution may qualify for programs they were previously unable to access due to being over-income. Institutional deeming is a valuable and underutilized healthcare financing option for families who don't qualify for government funded financial assistance or insurance programs based on income or who might be on a waiting list for a Medicaid waiver.

Under the provisions of TEFRA, Medicaid and SSI can offer support to children who have been hospitalized for an extended period, usually after 30 days. Through a process called "institutional deeming" these programs can become available to all children who qualify based on medical condition and length of stay in hospital. For children under the age of 18 or ages 18-21 and still in school, family income is not considered. Medicaid can help families pay hospital bills. This provision is especially helpful to privately insured families with high deductible plans who incur large charges during extended hospital stays.

This option is not offered in all states. Currently 18 states and the District of Columbia offer TEFRA (DE, DC [state-ish], GA, ID, ME, MA, MI, MN, MS, NE, NV, OK, RI, SC, SD, VT, WV, WI).

Additionally, AK and NH have programs that are very similar but don't fall under the TEFRA umbrella.

To start the institutional deeming process, speak to a hospital social worker.

Medicaid Waivers

Every state has a Medicaid Waiver program, known as Katie Beckett waivers, which allow a child with a disability to qualify for Medicaid regardless of that family's income. In order for a child to be eligible, the child must need the level of care provided in a hospital or a nursing facility or intermediate care facility. While each state must provide waiver services for children meeting the levels of care set forth by the Katie Beckett law, states also have a right to define hospital and intermediate levels of care using their own standards. Therefore, it is important to reach out to an expert in your state to learn which waivers might be available to your child. To locate Medicaid Waiver programs in your state, click [here](#).

Other Funding Options

Even with all the aforementioned programs, families still sometimes find themselves in need of financial assistance as a result of their child's special medical needs. Community Foundations, Townships Trustees, and Civic Organizations (Kiwanis and Lions) all have a record of helping families in need. On the national level, United Healthcare Children's Foundation is a nonprofit that provides grants to cover out-of-pocket medical expenses for children under the age of 17 that are either not completely covered or not covered at all by a family's private health insurance. This program is offered to families who meet their generous financial criteria and *are not currently receiving any government funded healthcare coverage*. Additional information and an online application can be found at <http://www.uhccf.org>.

Important to Remember

Programs and systems change frequently. It is important that you talk to someone whose sole job it is to remain well-versed in all systems and how they intersect to ensure your family is accessing all available programs. Hospital financial advocates are an excellent resource. The Federal Department of Health Services and Resources Administration also fund a Health Information Center in each state to help families navigate these services. To locate your state's Families-to-Families Health Information Center, visit www.familyvoices.org and click on your state on the homepage.

This information was generously provided by Rachael Alaniz, social worker, and FA parent. Thank you, Rachael.